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Cancer and Employment Issues: Perspectives from Cancer Patient Navigators

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Abstract

Among individuals diagnosed with cancer, 40% are working age adults who will face numerous challenges in returning to work, yet oncology providers report limited guidance and uncoordinated communication processes in addressing patients' work-related issues. Cancer patient navigators are uniquely positioned to fill this care and communication gap due to their focus on both practical matters and clinical care. This cross-sectional study utilized survey methodology to collect quantitative and qualitative data from 58 cancer patient navigators to (1) identify patients' cancer and employment issues that commonly challenge navigators and (2) identify the necessary training navigators felt would allow them to more effectively help patients deal with cancer and employment issues. Participants from the Southeast U.S. were invited to complete a paper survey while in attendance at a statewide cancer patient navigator conference or online via the state comprehensive cancer coalition's cancer patient navigator listserv. Results suggest financial burdens, work and treatment conflicts, taking unpaid leave for cancer care, and working through treatment were common concerns among their patients. Navigators also identified employment, legal, government programs, and financial resources as important training and education topics that would help them address their clients' employment and cancer conflicts. Given the fact that employment issues remain one of the most common unmet need of survivors and the increasing presence of navigators across the U.S., it is important to address the role of navigators in meeting patients' needs regarding cancer and employment and ensure they are provide with adequate training and resources.

Although cancer is the second leading cause of death in the U.S., survival rates have been steadily improving over the past 20 years due to earlier detection as well as advances in treatment and follow-up care [1-2]. Almost 70% of those who receive a cancer diagnosis today are still alive five years or more post-diagnosis and there are currently 14.5 million

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living Americans who have survived at least one cancer diagnosis in their lifetime [3]. Of those adults diagnosed with cancer each year, the near majority of them who were employed prior to their diagnosis will return to work at some point during or after their cancer treatment[4]. However, the return to work is fraught with challenges, including adjustments to work hours or work role, learning to cope with new physical and/or cognitive limitations, and/or fear of being terminated [5]. Moreover, cancer survivors may continue to work and/or postpone retirement plans for financial reasons or to maintain their health insurance [5]. Compared to those with no history of cancer, survivors experience significantly more medical costs, greater losses in average productivity, increased levels of unemployment, greater risk of disability, and reduced earnings [6]. This is problematic considering the ability to work and remain employed is related to overall quality of life [2], and work may hold even greater meaning for cancer patients because quality of life is critical to survivorship [6].

Employment issues are cited as one of the most common unmet psychosocial needs of cancer survivors [7]; specifically, patients indicate they want more information on how to navigate the return to work [8-9]. Yet, most oncology care providers feel limited in their ability to address this topic with patients [10], citing minimal guidance, limited access to resources they feel clients need to achieve work-related goals, and concerns regarding their mastery of knowledge of how cancer may impact work [10-11]. Additionally, communication between members of the oncology team on this topic may be uncoordinated; for example, some team members may assume that another team member will address work-related issues and others may avoid the topic out of concern that another professional would overrule their suggestions [10].

Notably, there is one key member of the oncology team that may be uniquely positioned to fill this care and communication void related to patients' employment concerns and that is the cancer patient navigator. Overcoming clinical and psychosocial barriers to care and coordinating care among oncology team members are the main goals of cancer patient navigators [12]. Although introduced in the 1990's to reduce health disparities in underserved populations by working with patients to reduce delays in care [13], their focus has expanded to include improving the cancer experience for patients and their family members across the entire continuum of care, including survivorship [14]. Patient navigators, now ubiquitous across U.S. cancer programs and often required for accreditation purposes [15-16], inhabit a unique role on the oncology team as they bridge the gap between the social and medical needs of clients [17]; they are poised to play a key role in addressing issues pertaining to cancer and employment.

However, there is minimal research addressing the role of cancer patient navigators in assisting patients with cancer and employment concerns or the training they would need to help patients with work-related issues, although multiple studies have established the importance of their role as a member of the oncology team [18-19]. This study sought to address these gaps in the literature with the following aims: (1) identify patients' cancer and employment issues that commonly challenge cancer patient navigators and (2) identify the necessary training navigators felt would allow them to more effectively help patients deal with cancer and employment issues.

Method

Study Overview

This cross-sectional study utilized survey methodology to collect quantitative and qualitative data from cancer patient navigators regarding the employment issues commonly faced by their clients and their perspectives regarding education and training that would allow them to more effectively address patient concerns related to work and cancer. Cancer patient navigators were recruited for this study via non-probability, convenience sampling. Eligibility criteria included the following: (1) age 18 or older and (2) currently employed as a cancer patient navigator or employed in a related profession and interested in cancer and work-related issues. Participants were recruited through two separate methods; they were either invited to complete the survey while in attendance at a statewide cancer patient navigator conference (October 2014) or they were invited by way of an email listserv consisting of cancer patient navigators hosted by the state comprehensive cancer coalition. Participants at the conference completed the survey in paper format, while those from the listserv completed the survey online. Online and paper versions of the survey were identical and a total of 58 cancer patient navigators completed the survey. The study protocol was approved by an Institutional Review Board.

Measures

Patient employment issues—Cancer patient navigator perceptions regarding which cancer and employment issues their clients face were assessed with two questions. The first question consisted of a 15-item checklist (e.g., short- and long-term disability, financial burdens, Family and Medical Leave Act [FMLA], job termination) in which respondents were asked to select *all employment related issues* they have observed in their work with cancer patients. The checklist also allowed participants to write an open-ended response, if they found that a common employment issue was not listed. All 15 items were selected from the literature [4-5] and the practical expertise of the investigators as commonly reported employment issues reported by cancer patients. The second question was an open-ended question in which respondents were asked to identify the *most frequent issue* that comes up with their patients regarding work and cancer.

Patient navigator education and training—Education and training that patient navigators felt would be most beneficial to them in helping their clients manage work and cancer issues was also assessed with two questions. The first question was open-ended and asked respondents to write in the type of training and education they felt would help them in addressing employee issues with their cancer patients. The second question asked respondents to check their preferred training modality from a list of pre-filled choices (i.e., webinars, conference calls, in-person meetings, continuing education credits units [CEU], other), allowing them to check more than one option if applicable.

Demographic and job characteristics—Participants were asked to provide standard demographic data (e.g., age, race/ethnicity, educational background). Participants were asked to provide information regarding job characteristics, including job tenure, organization type (i.e., hospital, health department, clinic/doctor's office, other), geographic city or county

of job, cancer continuum focus area (i.e., screening, early detection/diagnosis, treatment, survivorship), and cancer site(s) (e.g. all sites, breast only, colon/gastrointestinal only) for which they provided navigation services.

Analysis

Univariate analyses were used to evaluate demographic characteristics and close-ended questions. Open-ended questions were coded into relevant higher order themes and sub-themes and analyzed through qualitative content theme analysis [20]. After the initial coding scheme was developed by the research team, analysis was conducted by each team member individually and then compared, ensuring group consensus to improve reliability.

Results

Cancer Patient Navigators

The study participants were primarily female (91%) and Caucasian (100%) with an average age of 47 years ($SD = 10.3$) (Table 1). The majority of participants identified as nurses (60%) and social workers (17%). Participants were employed in hospitals (43%); insurance companies, government agencies, or nonprofit organizations (31%); clinics or doctor's offices (21%); and/or health departments (14%). Participants' cancer continuum focus included treatment (66%), early detection/diagnosis (62%), screening (53%), and/or survivorship (53%). The vast majority of navigators provided services to individuals diagnosed with all types of cancers (62%), while others exclusively provided services for patients diagnosed with specific cancers outlined in Table 1.

Patient Employment Issues

Primary employment issues—As noted in Table 2, the top four employment issues that navigators faced in their work with cancer patients were financial burdens (81%), conflicts between work and treatment (55%), working through treatment/returning to work soon after treatment (48%), and taking unpaid leave to receive care (48%). A significant number of navigators also indicated that their clients faced a range of other employment-related issues which are further detailed in Table 2. About 17% of survey participants reported they do not see any employment-related issues with their cancer patients.

Most frequent work-cancer issues—Qualitative responses to this open-ended question clustered around four primary themes: financial burdens, work leave, insurance issues, and work-cancer fit. Specifically, financial burdens included four sub-themes: general financial burdens, issues pertaining to economic security, payment for cancer treatment and care, and payment for ancillary costs associated with cancer care.

Financial burdens: Within the first primary theme – financial burdens – respondents identified the generic term “financial burdens” as the most frequent employment issue that their cancer patients experience. Related to the second sub-theme, participants specifically outlined issues pertaining to economic security, including disruption in patients' income presumably due to taking leave from work for cancer treatment and recovery and/or the potential for job loss. One patient navigator rhetorically posed the question, “If they [my

patients] can't work, how are they going to pay bills and survive financially?" Specific patient concerns included the inability to pay routine bills (e.g., rent, utilities), loss of income, general lack of financial resources, and the need for financial assistance.

Responses that grouped within the third financial burden sub-theme – payment for treatment and care – highlighted the range of concerns that cancer patients have about paying for their cancer care either because of taking time off from work or because of the general expense of cancer care. Another navigator cited the concerns of insured patients “that are faced with tremendous costs not covered by insurance”, while others included concerns regarding medication cost, lack of money to pay for cancer care or medical visit copayments, and retired patients returning to work to afford treatment. Payment for ancillary costs associated with cancer care – the fourth financial burden sub-theme – identified additional expenses that patients experience due to cancer care (e.g. transportation.)

Work leave: Some participants reported their patients were concerned with taking a leave from work for treatment and recovery, with or without pay, including one respondent who stated that patients who take a leave from work worry “about not having a job when [they are] ready to return”. Additional concerns included insufficient sick and/or vacation leave, loss of health insurance benefits, and a reduction in work hours.

Insurance issues: Participants reported that some their patients were afraid of losing health insurance if they missed too much work with or without paid leave or if they reduced their work hours. Patients were also concerned with maintaining health insurance, short-term disability issues, and having to stay in their job due to receipt of health insurance benefits (i.e., job lock).

Work-cancer fit: The last primary theme encompassed issues encountered by patients as they integrated their work responsibilities and their cancer care. One respondent reported that patients face “no flexibility with [their] job during treatment”, while another stated that patients are concerned “regarding [their] ability to perform duties when they return to work”. Additional issues frequently faced by patients included the following: getting time off from work for treatment and appointments, ability to work while receiving treatment, managing short and long-term side effects, managing work and treatment schedules, balancing treatment and work, lack of workplace support and understanding of cancer treatment, and returning to work too soon before fully recovering.

Patient Navigator Education and Training

Education and training topics—Patient navigators identified several education and training topics that would help them address the employment issues faced by their cancer patients. These topics grouped into five broad areas: employment, legal, government programs, financial, and miscellaneous (Table 3). Employment topics included the following: (1) where to refer patients to address their employment concerns, (2) how to work with employers, (3) how to help patients manage cancer care and work responsibilities, and (4) policies that could help patients successfully manage their work and cancer care such as FMLA.

Legal topics about which patient navigators requested information pertaining to (1) employment laws that protect employed cancer patients (i.e., American Disabilities Act), (2) laws that specify workers' rights pertaining requesting time off for health-related matters (i.e., FMLA), and (3) laws that create opportunities for workers to be retrained if unable to return to their pre-cancer occupation.

Government-related topics included the following: (1) eligibility criteria and application process for federal health insurance and disability programs and (2) criteria and procedures involved in moving from private to public insurance or from short or long-term disability to social security disability insurance. Financial topics included the following: (1) budgeting and financial management, (2) assessing patient financial needs, and (3) accessing more detailed and up to date information about additional grants, funding opportunities, or other financial resources that could assist cancer patients in paying for cancer care. Other miscellaneous information about which patient navigators requested information included: (1) requirements for a handicap parking permit, (2) general cancer survivorship issues, and (3) local, federal, and state resources that can help patients navigate and manage employment and insurance issues.

Preferred training modality—Almost 85% of participants preferred to receive training either by webinar or conference call. The third most popular method of training was in-person meetings, selected by 48% of the patient navigators. Over half of the participants (57%) indicated they would like to receive CEUs for education and training on cancer and employment issues.

Discussion

This study makes an important contribution to the literature by providing detailed information on cancer patient navigators' assessment of the cancer and employment issues faced by their clients as well as navigators' training needs on the same topic. Similar to other research [18, 21], navigators in this study reported that financial burdens, work leave, insurance, and work-cancer fit were common concerns among their patients, with more nuanced findings highlighting the significant monetary burden cancer and its treatment places on patients [17]. Feedback from the navigators indicated a complex interplay of employment challenges that threaten the financial and overall wellbeing of patients. These challenges have the potential to influence patients' successful completion of cancer treatment, and can impact health outcomes, career trajectories, and job security.

Employment issues can have a significant impact on the lives of cancer patients, yet many patient navigators in this study indicated that they did not feel equipped to provide the necessary guidance to patients regarding these issues. As such, it is evident training, education, and resources are needed to help navigators understand the work, legal, governmental, financial, and insurance matters commonly faced by employed cancer patients and to assist patients in successfully co-managing cancer care and employment. On a micro level, patient navigators must be prepared to help patients access the financial resources necessary to afford cancer treatment and meet other financial obligations, especially when treatment requires patients to reduce their work hours. On a mezzo level,

navigators help support patients in addressing day-to-day work-cancer care challenges such as scheduling medical appointments that coincide with one's work schedule, requesting workplace accommodations through their human resources department or supervisor/manager, and managing side effects that could negatively impact work performance. Formalized training on these topics could help patients more effectively manage cancer care and employment responsibilities [10]. On a macro level, many of the patient navigators in this study expressed concern regarding their lack of detailed legal or public policy knowledge, making training on supports offered by federal and state policies that can assist employed cancer patients (e.g. Family Medical Leave Act (FMLA) and Americans with Disabilities Act (ADA), Social Security, Medicare, Medicaid, etc.) vital to the success of patient navigators. Professional organizations (e.g., National Cancer Legal Services Network), academic centers (e.g., George Washington University's Executive Training on Navigation and Survivorship), and non-profit groups (e.g., Cancer and Careers; American Cancer Society; National Coalition for Cancer Survivorship) are well-poised to provide CEU offerings to support the educational needs of patient navigators and potentially other healthcare professionals working with patients navigating chronic illnesses.

Navigators are an ideal member of the oncology care team to help patients manage the challenges of managing work and cancer, considering they are pivotal to the provision of care beyond defined clinical necessity [17]. Indeed, patients who work with navigators have reported that they are better prepared for the future, have a greater understanding of how cancer impacts their lives, and are more engaged in their care [22]. However, it is imperative that navigators be prepared with the necessary knowledge and resources concerning cancer and employment, so they can proactively identify and address the challenges that their employed patients are likely to encounter in this area, and are able to work effectively with employers within the context of Health Insurance Portability and Accountability Act (HIPAA) guidelines.

Limitations and Directions for Future Research

This study provides important results regarding the cancer and employment issues faced by patients which commonly challenge cancer patient navigators as well as the training these navigators feel would be most helpful in addressing these issues. However, there are several study limitations that should be considered. This study was conducted in one state, with a small and largely homogenous sample; therefore, generalizability may be limited. Although we consider the patient concerns reported by navigators regarding cancer and employment to be accurate, they may not perfectly reflect all patient concerns in this area. Additionally, related to scope of practice, we did not collect information on overall tenure as a navigator or the number of patients seen annually, and navigator experiences may differ in relation to these factors. These limitations are largely reflective of the exploratory nature of this study, however, they provide valuable guidance for future research.

Given the increasing importance of patient navigators in the delivery of cancer care, it is interesting to observe the varying definitions of navigation, the lack of consensus regarding what patient navigators do, and inconsistency in required job qualifications [12]. As the navigator role evolves, it is essential that any job changes are based on empirically sound

evidence [23] and future research should guide this role development by further defining how navigators handle the cancer and work concerns of their patients. Future studies could expand the current findings by the systematic study of nationally representative samples, as well as examining the variation in responsibilities of navigators due to educational background and training. Agreement regarding the training needs of navigators has also yet to be reached [12, 24], providing a key opportunity to include resources regarding the effective management of cancer and employment in the training provided to navigators that is currently under development.

Despite the limitations of this study, our findings regarding the challenges cancer patient navigators encounter when helping patients with cancer and work issues and the training they feel is necessary to surmount these challenges is an important contribution to the field of patient navigation. Cancer patient navigators have the potential to fill the gap that has historically existed between what providers offered, in terms of work-related guidance, and what patients felt they needed, creating a connection between our fragmented health care system and the complicated biopsychosocial needs of patients [25]. Given the increases in cancer survival rates, [1-2], the fact that employment issues remain one of the most common unmet need of cancer survivors [7], and the increasing presence of patient navigators in U.S. cancer programs [15-16], it will only become more important to address the role of navigators in meeting the needs of patients regarding cancer and employment and ensuring they have the needed training and resources to do so in an effective manner.

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Table 1

Sample and job characteristics of cancer patient navigators (N = 58)

Variable	<i>n</i> (%)
Gender	
Female	53 (91.0)
Male	5 (9.0)
Race	
Caucasian	58 (100.0)
Geographic location	
Metropolitan	31 (54.4)
Educational background	
Nurse	35 (60.3)
Social work	10 (17.2)
Counselor	2 (3.4)
Other profession	11 (19.0)
Place of employment *	
Hospital	25 (43.1)
Clinic/doctor's office	12 (20.7)
Health department	8 (13.8)
Other (insurance agencies, government, etc.)	18 (31.0)
Cancer care focus *	
Treatment	38 (65.5)
Early detection/diagnosis	36 (62.1)
Screening	31 (53.4)
Survivorship	31 (53.4)
Cancer site(s) focus *	
All types of cancer	36 (62.1)
Colon/gastrointestinal	10 (17.2)
Lung/thoracic	8 (13.8)
Breast	8 (13.8)
Cervical	5 (8.6)
Head and neck	1 (1.7)
Melanoma	1 (1.7)
Other chronic disease	1 (1.7)

Mean (SD) [Range]

Age (in years) 46.95 (10.3) [27-68]

Job tenure (in years) 4.32 (4.14) [1-20]

Note.

* Responses categories are not mutually exclusive

Table 2

Patient employment issues as perceived by cancer patient navigators (N = 58)

Variable	n (%)
Financial burdens	47 (81.0)
Conflicts between work and treatment schedules	32 (55.2)
Working through treatment/returning to work soon after	28 (48.3)
Taking unpaid leave to receive care	28 (48.3)
Job lock	25 (43.1)
Managing short and/or long-term side effects at work	25 (43.1)
Short and long-term disability insurance	24 (41.4)
Job termination	18 (31.0)
Lack of workplace accommodations	14 (24.1)
Protections under the Family and Medical Leave Act (FMLA)	12 (20.7)
Lack of supervisor support	11 (19.0)
Do not perceive employment-related issues with patients	10 (17.2)
Lack of patient provider communication	9 (15.5)
Lack of coworker support	6 (10.3)
Protections under the Americans with Disabilities Act (ADA)	6 (10.3)
Discrimination	5 (8.6)
Other	4 (6.9)
Transportation	1 (1.7)

Note. Respondents selected all applicable issues, hence categories are not mutually exclusive

Table 3

Education and training topics that would help cancer patient navigator and preferred training modality (N = 58)

Theme	Topic
Employment	Where to refer patients about employment concerns How to work with employers How to help patients manage cancer care along with work responsibilities Policies that could help patients in managing work and cancer care (i.e., FMLA)
Legal	Employment laws and regulations that could protect employed cancer patients (i.e., ADA) Laws that specify workers' rights pertaining requesting time off for health related matters (i.e., FMLA) Laws that create opportunities for workers to be retrained if unable to return to their pre-cancer job
Government	Eligibility criteria for federal health insurance and disability program Criteria/procedures to move from private to public insurance or from short/long-term disability to SSDI
Financial	Budgeting and financial management Assessing patient financial needs Information about additional financial resources to help patients pay for care, medications, and insurance copays
Miscellaneous	Requirements for a handicap parking permit General issues about cancer survivorship Local, federal and state resources that can help patients navigate and manage employment and insurance issues